

**ISSUE NO:- 01/ 2018**

# BULLETIN



## EVENTS

### Drop-In:-

Greens Lane Methodist Church, Hartburn. We meet here 1pm to 4pm on a Tuesday. Alternative therapy is available for those who enjoy or would like to try Shiatsu.

### Social Evenings:

These are held at the Orthoptic Supplies, 176 Belasis Avenue, Billingham, TS23 1EY, on the last Wednesday of every month at 7pm.

### Shopping Online????

Buy items or book holidays through the Stockton MS Group web site and we will receive a donation. There are over 100 top retailers to choose from. It all helps raise funds for the group.

### Monthly Bulletin

"If you would like to receive this bulletin by email, then just send a request to [news@stocktonmsgroup.org.uk](mailto:news@stocktonmsgroup.org.uk).

Remember if you change your email address to let us know by sending a message to [news@stocktonmsgroup.org.uk](mailto:news@stocktonmsgroup.org.uk)"

### Group Contacts

Carol 617864

Web address:- [www.stocktonmsgroup.org.uk](http://www.stocktonmsgroup.org.uk)  
e-mail: [info@stocktonmsgroup.org.uk](mailto:info@stocktonmsgroup.org.uk)

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### **Thousands of benefit claimants with Multiple Sclerosis told they are 'not disabled enough'**

Thousands of benefit claimants with multiple sclerosis have been told they are "not disabled enough", a charity warns today.

New figures show the huge number of people with MS - a progressive, long-term condition with no cure - who have claims for Personal Independence Payment (PIP) rejected.

The benefit pays up to £141 a week to help people cover the extra costs of being disabled or long-term sick.

But since it launched in 2013, 31% of new claims by people with MS - 4,100 in total - have been "disallowed", it's claimed.

A further 6% (1,100) are said to have qualified for PIP initially, but were later rejected following a reassessment.

The figures, obtained from the government under Freedom of Information laws by the MS Society, come after a string of complaints about the quality of assessments for the benefit.

Protesters say medical evidence is often missed in the process, and 65% who appeal to an independent tribunal win their case.

Thousands of people **who scored no qualifying points at all** in assessments have won appeals to get PIP.

MS sufferer Bethan Thorpe, 41, who was denied the benefit in 2014 only to win the highest rate of PIP at a tribunal, said: "The assessor wasn't aware I had MS and obviously hadn't read my medical reports.

"When I saw my report of the assessment, I was shocked to see I'd been marked down for being able to shake the assessor's hand, and for carrying a handbag.

"I was made to feel like a liar about my condition; it was so demoralising.

"For almost a whole year I had no income while I was fighting this decision.

"My health suffered tremendously in that time, as stress makes my symptoms worse. Without PIP I couldn't even get to my hospital appointments."

Today the MS Society warns the entire system of assessments - which private firms carry out **at a cost of hundreds of millions of pounds a year** - is "fundamentally flawed".

Chief executive Michelle Mitchell said: "It's insulting that so many people who are diagnosed with a long-term, incurable condition are being told they don't qualify for support.

"The Government needs to review the whole system to make sure it works more effectively for those it's designed to support.

"Having MS is hard enough; it shouldn't be made harder by a welfare system that doesn't make sense."

A Department for Work and Pensions (DWP) source said new evidence in Ms Thorpe's case was only submitted a month before her appeal hearing.

A spokeswoman said: "PIP assessments look at how individuals are affected by conditions such as multiple sclerosis over the majority of days in a year, rather than just assessing ability on a single day.

"Under PIP, 36% more people with multiple sclerosis receive the highest rate of support than under the previous DLA system.

"More than 2.6 million PIP decisions have been made, and of these 8% have been appealed and 4% have been overturned. In the majority of successful appeals, decisions are overturned because people have submitted more evidence."

## **Multiple sclerosis patients to have routine access to beta interferon drug, says NICE in new draft guidance.**

Multiple sclerosis drug, Extavia, has been approved for routine funding on the NHS, in NICE draft guidance.

A discount to the price of this drug now means it can be recommended as a cost effective option for adults with relapsing- remitting multiple sclerosis (MS) or secondary progressive MS with continued relapses.

Affecting around 116,000 people in England, MS is a chronic and disabling condition affecting the brain and spinal cord.

Relapse-remitting MS is where people have distinct symptoms, such as vision problems or difficulty keeping balance, which then fade away either partially or completely. Secondary progressive MS is the stage after relapsing remitting MS where the disability steadily gets worse.

Extavia is self-injected every 2 days and works by slowing down the damage to the nervous system caused by MS and by reducing the number of MS related relapses. The committee noted evidence that suggested drugs of this type become less effective over the first 2 years. As part of this appraisal NICE did not recommend MS drugs glatiramer acetate and the other beta interferons (Avonex, Betaferon, Plegridy and Rebif), as they were found to be not cost effective.

**Professor Carole Longson, director of the centre for health technology evaluation at NICE, said:** "Multiple sclerosis is lifelong condition that can limit people's ability to work, and to engage in social and family life. Being able to delay the progression of the disease is important to help patients get back to their normal lives.

"We are delighted that Novartis has been able to agree a reduction to the price of Extavia to allow it to be made routinely available to people with this type of multiple sclerosis.

"We are keen to work with the companies for the other drugs to ensure that patients continue to benefit from a choice in treatment for multiple sclerosis."

Extavia has a list price per patient per year of £7,259 however the discounted price that was approved remains confidential.

Before this appraisal beta interferons and glatiramer acetate were available on the NHS through the Department of Health's Risk Sharing Scheme (RSS), which has now ended.

These recommendations are not intended to affect treatment that was started in the NHS before this guidance was published.

The draft guidance is open for consultation until 24 January 2018.

## **The Untreatable Has Become Treatable**

By: Professor Alasdair Coles MS researcher, University of Cambridge

There are 100,000 people living with MS in the UK. I can see a future where all of them can access effective medication

*"Multiple sclerosis is untreatable, and research into treatments of the disease is the graveyard of many promising careers."*

Or so I was told by a respected neurologist in 1993. I was not to be put off though, and soon afterwards joined a team in Cambridge researching a new treatment for MS.

We were working on an antibody that killed off lymphocytes – one of the white blood cells that fight off illness. We believe these cells are responsible for relapsing multiple sclerosis (MS), the most common form of the disease. People with relapsing MS experience attacks, often lasting weeks, of symptoms such as numbness, weakness, unsteadiness or difficulty with vision. Mostly, young adult women are affected.

Twenty-one years later, the drug we were investigating was licensed, approved by NICE and being given to people in UK and Europe, followed by the United States one year later. Today it's known as alemtuzumab, and treats many thousands of people around the world. As well as alemtuzumab, a person newly diagnosed with relapsing MS could today be offered up to fourteen different treatments, ranging from injections, to infusions, tablets and even bone marrow transplantation.

We have come a long way, and 2017 has been a particularly exciting year. We had another new treatment emerge for relapsing MS called *cladribine* – the apogee of convenience. People need to take only a handful of tablets over two weeks in two consecutive years and then – hopefully – will not need any more. Astonishing.

The most exciting news of 2017 is that a drug called ocrelizumab was licensed for a rarer form of MS, called *primary progressive*. In this type of MS people do not experience attacks that come and go. Instead they feel their mobility, or balance, or vision, very slowly deteriorate, year by year. We are waiting to hear whether NICE judges ocrelizumab to be cost-effective for the NHS. If approved, it will be the first time people with progressive MS have medication available to them.

For my research group, 2017 is a turning point. Like many researchers, we are now investing our energies into ways to repair damage done by the disease. We have known for a few years that stem cells in the brains of people with MS are potentially capable of rebuilding myelin, but for some reason they do not. Luckily a colleague, Robin Franklin, has worked out that we can wake these stem cells up by stimulating a particular receptor in the brain.

The really good news is that we can quickly test his theory because there is an approved skin cancer drug that acts on this receptor: bexarotene. We have started a small trial of bexarotene in fifty people with MS and, if successful, we can *repurpose* bexarotene as an MS brain-repair treatment.

The MS Society's Christmas appeal hopes to fund not one but three trials in which licensed drugs are repurposed to promote brain repair or prevent brain damage in MS – this includes our trial of bexarotene. The tantalising prospect is that if just one of these drugs proves to be effective, it could become part of the standard treatment pathway much sooner than if we were starting from scratch. Meaning more effective treatments would be available for MS, faster. There are 100,000 people living with MS in the UK. I can see a future where all of them can access effective medication, and are offered a package of drug treatments. Some of these might be treatments that target the immune system to prevent more attacks on the brain, and others will encourage resident stem cells to repair the damage that has already been done. This is quite a prospect for a disease that was declared untreatable twenty-four years ago.

***Alasdair Coles is the lead investigator of the bexarotene trial, which will be funded by the MS Society's Christmas appeal. To donate, visit [www.mssociety.org.uk/elf](http://www.mssociety.org.uk/elf).***

#### **DISCLAIMER**

Articles in this Bulletin are meant for the sole purpose of information only and do not necessarily reflect the views of the committee.

## **U.K. Survey Supports Likelihood of Link Between Chicken Pox-Shingles Virus and MS**

A large U.K. survey assessing the frequency of chickenpox and shingles in multiple sclerosis (MS) patients suggests a link between these diseases and MS, researchers report, suggesting their findings could help in decisions regarding immunosuppressive treatments and varicella-zoster virus vaccinations.

Results of the study "Prevalence of a history of prior varicella/herpes zoster infection in multiple sclerosis" were published in the *Journal of Neurovirology*.

The exact cause of MS eludes scientists, but several studies show the disease is based on complex interactions between environmental and genetic risk factors. Among environmental factors, several viruses have been implicated in MS development.

The varicella-zoster virus (VZV), which causes chickenpox, remains in the body after a first infection, staying dormant in nerves around the spinal cord. Later in life, the virus can reactivate and cause a disease known as shingles.

Shingles occurs more frequently in immune-compromised individuals, and treatment with newer disease-modifying and immunosuppressive medications in MS patients have been linked to the virus' reactivation.

Long-lasting immunity to VZV infection is mediated by T-cells (a type of immune cell that fights infection), and newer treatments targeting T-cells can potentially reduce immune responses against VZV.

"Given that the use of new generation disease-modifying treatment is rapidly growing and that these treatments are known or likely to affect immune surveillance and responses against VZV, it is important to know the prevalence of a history of VZV exposure, as a primary infection (i.e., a history of chickenpox) or as a reactivation (zoster) [shingles] in MS patients," the team wrote. To assess the frequency of chickenpox and shingles in MS patients, researchers surveyed using questionnaires 1,206 randomly selected MS patients registered with the Nottingham University Hospital MS clinics.

Answers were returned from 605 patients, with a mean age of 53. None were using immunosuppressive treatments.

The majority — 86 percent — reported having had chickenpox, which is comparable with what is expected for the general population. Seventeen patients (3 percent) reported that the episode of chickenpox occurred after the onset of MS.

"The existence of a minority of MS patients who have not been exposed to VZV and who acquire the primary infection after the onset of MS needs to be taken into account in therapeutic decision-making processes," the researchers wrote.

"It also suggests that vaccination against herpes zoster could be considered in people with MS, in particular in those about to be treated with disease-modifying drugs potentially affecting VZV responses," they added.

Of the 594 patients who answered the shingles part of the questionnaire, 104 (17 percent) reported at least one episode of shingles. Researchers found this figure to be higher than expected in a matched general population — and noted that no difference in shingles rates was seen between male and female patients.

"The higher frequency of shingles in our MS population cannot be explained by the higher proportion of females, suggesting a real difference," they wrote.

More than half of the patients with history of shingles also had the disease prior to developing MS.

"The substantial proportion of subjects who had a history of zoster before the development of MS suggests the virus as a possible risk factor for MS or marker of an immune response that predisposes to MS. Moreover, a history of zoster infection seems to be more common in people with MS than would be expected in a general MS population," the team concluded.

## Tanni Grey-Thompson told there was 'no room' on train for her

Paralympian Baroness Tanni Grey-Thompson has said she was stopped from boarding a train after a passenger told staff there wasn't space for her.

She said in a **tweet**: "Merry Christmas to the person on the train who just stopped me getting on. Told member of staff 'there's no room for her'."

"Everyone else waiting on the platform got on," added Baroness Grey-Thompson, a wheelchair user with 11 gold medals.

The athlete explained in further tweets that the passenger "wouldn't move".

Baroness Grey-Thompson, 48, said this put the member of train staff in an "awkward position".

She later returned to Twitter to say she would not be commenting further on her experience, and described her original tweet as "a moment in time".

But she did pay tribute to the "lovely" station staff.



Image Copyright @Tanni\_GT @TANNI\_GT



Image Copyright @Tanni\_GT @TANNI\_GT

News of the incident was greeted with shock by other social media users, including the columnist Grace Dent - while some questioned why the train staff had not intervened. Baroness Grey-Thompson, one of Britain's most successful disabled athletes, was named a Life Peer in 2010 and also **sits on the BBC Board**.

Since retiring in 2007, the Cardiff-born athlete has become the patron of numerous charities, including Sportsaid Foundation and the Duke of Edinburgh Awards scheme, and was appointed Chancellor of Northumbria University.

## **Young MS sufferer was in home for elderly people**

A woman has called for better care for young disabled people after her sister had to share a care home with people more than twice her age.

Before 38-year-old Joanne Head died in 2015, she had to have 24-hour care due to advanced multiple sclerosis.

Her sister Vicky Cook, from Nottingham, said most residents in the home were over 65 and some had dementia.

Lincolnshire County Council, who provided the care, said it works with families to find the right placements.

Mrs Cook said it was "horrible" to see her sister in an environment where no suitable therapies or social interaction and activities were offered.

She said her sister was "full of life" and working as a marketing manager in London when she was diagnosed with relapsing remitting multiple sclerosis (MS), in 2008 at the age of 31.

"After two years she struggled to walk, [the MS] affected her bladder control, her memory, she suffered from tiredness.

"She became someone who didn't want to leave the house."

In 2012, Ms Head moved back home to Boston, Lincolnshire, before developing secondary progressive MS.

Ms Cook said her sister's cognitive ability had deteriorated, her speech was reduced to just "yes" and "no" and she sounded "muddled" because she was losing her short-term memory. She needed 24-hour care and was placed in a mixed age home at 35, but most of the residents were over 65.

"It was horrible to see your younger sister there with people with dementia and unsettling behaviour," said Ms Cook.

"She shouldn't have been there. It wasn't dignified."

Ms Head was later moved to a home that was more suitable, with more activities and social evenings, but was still at least 10 years younger than the other residents.

The MS Society said the social care system was "failing" thousands of younger disabled adults. The charity said only 32% of 18-29 year olds with MS had all their care needs met and it was "fundamentally wrong" that younger adults with the condition were living in older people's care homes.

One in seven younger disabled adults in residential care could be in homes for older people, a spokesperson said.

Lincolnshire County Council, who provided Ms Head's care, said while they could not comment on the details of individual cases, a wide range of factors were explored to ensure the appropriate placement was made.

It said a number of care homes were registered units for both under 65s and over 65s, and many specialised in specific types of care depending on an individuals' needs.

## **Secret Teacher: doctors said MS would end my career – they were wrong**

I was in my first year of teaching when I was diagnosed with multiple sclerosis. I knew life would never be the same, but desperately wanted to keep working

It was New Year's Day when I woke with pins and needles in my hand. I didn't think much of it at first, but two days later my hand had seized up and I couldn't even hold a pen. The day after that, I was struggling to walk in a straight line.

I saw the GP and was admitted to hospital for a series of tests. By this time, I couldn't even feed or dress myself.

The consultant neurologist was blunt in his delivery of my diagnosis. "There are lesions on your brain," he said. "It's clearly multiple sclerosis (MS). You should follow a different career – you won't be able to be a teacher."

MS is an auto-immune disease that affects the brain and spinal cord – there is currently no known cure. My life was going to change, and my mind was filled with questions. Was I going to end up in a wheelchair? Should I give up teaching, even though I was only in my NQT year? Then I became defiant. There were surely other teachers who had similar conditions. I realised, despite the stress of the job, I did still want to be a teacher. What I didn't want was to let MS dictate my choices in life.

After physiotherapy and steroids, I regained most of my mobility and went back to school on a reduced timetable. I shared my news with the head of my department, senior leadership team and a few colleagues but made the decision not to go public with my diagnosis.

One of the difficulties about living with MS is that many of the symptoms are invisible yet crippling – fatigue, loss of sensation and bladder problems, for example. Although my occupational health therapist made some recommendations to help me, the school was reluctant to follow them. I had to fight hard to have a short morning break so I could sit down between lessons. I wasn't asking for any favours or for an easy life – I just wanted to be able to do my job.

I searched for ways to be more efficient and still deliver great lessons. I prioritised my planning and stopped sweating over the small things. I started a yoga class and restricted the amount of work I did outside of school. I began to accept I would sometimes have to take time off – and realised that on my worst days, I had to put my health first. Not enough teachers do that at the best of times.

Looking back I can see that I was in a dark place emotionally for those first few years. I was terrified of having a relapse and found the unpredictability of MS hard to deal with. But teaching gave me a focus and a routine. I had little time to dwell on my circumstances and I thrived on connecting with pupils and finding new ways to teach a skill or concept. I became determined to prove my doctor wrong.

All this became significantly easier when I moved to another school with a more supportive environment. Its leadership team believed that – as far as possible – evenings and weekends were for personal time. They ensured our department never had any full days of teaching so we could carry out extracurricular commitments. I was able to discuss any concerns and felt respected and valued. The school also had a nurse who I could speak to in confidence and who would liaise with the senior leadership team when extra help or changes to my timetable were needed. Having her there was a weight off my mind.

I'm proud of myself for not giving up. But finding a school with a more welcoming and inclusive culture was, without a doubt, also a huge factor in my decision to stay in teaching for longer. There is growing awareness of teacher wellbeing, and with good reason, but I believe we still have a long way to go. Teachers give so much of themselves to the job, and we need all leaders to be ready to provide assistance when we're having difficulties, whatever they may be. I knew that I wanted to make a difference in children's lives and be a teacher they would remember, and I'm glad I stayed. Over time, I've found ways to manage my health, too. I now do 10K runs for charity and my latest MRI scan showed no sign of the disease progressing. At this moment in time, I'm considered too well for treatment. I can scarcely believe how far I've come.



# YOUR JOKES

Hilary Clinton decided to send Donald Trump a letter to let him know how she felt about him. Trump opened the letter and it appeared to contain a single line coded message; 370HSSV 0773H  
Trump was baffled, so he e-mailed it to Vanessa Trump and his children. Vanessa Trump and the children had no clue either, so they sent it to the FBI.  
No one could solve it at the FBI, CIA or NASA. They eventually asked Britain's MI6 for help. Within minutes, MI6 cabled this reply: "Tell Mr Trump that he is holding the message upside down."

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My husband and I were happy for twenty years; then we met.  
I find it ironic that the colours red, white, and blue stand for freedom, until they're flashing behind you.  
Today a man knocked on my door and asked for a small donation towards the local swimming pool, so I gave him a glass of water.  
If I had a dollar for every girl that found me unattractive, they'd eventually find me attractive  
If you can smile when things go wrong, you have **someone** in mind to blame.  
Doesn't expecting the unexpected mean that the unexpected is actually expected?  
I hate it when people use big words just to make themselves sound perspicacious.  
Hospitality is the art of making guests feel like they're at home when you wish they were.  
I bought a vacuum cleaner six months ago and so far all it's been doing is gathering dust.  
Behind every great man is a woman rolling her eyes.  
If you keep your feet firmly on the ground, you'll have trouble putting on your pants.  
When I married Mr. Right, I had no idea his first name was Always.  
My wife got 8 out of 10 on her driver's test--the other two guys managed to jump out of her way.  
There may be no excuse for laziness, but I'm still looking.  
Give me ambiguity or give me something else.  
He who laughs last thinks slowest.  
Is it wrong that only one company makes the game Monopoly?  
I was going to give him a nasty look, but he already had one.  
Change is inevitable, except from a vending machine.  
If at first you don't succeed, skydiving is not for you.  
Money is the root of all wealth.

## MEMBERS COMPETITION

A £5 prize will be given to the member whose entry has the most correct answers. Even if you do not answer all the questions, send in those you have answered – you could still win!

- 1/ How many finger holes does a recorder have running down the front of the instrument? .....
- 2/ Peter Benchley wrote a novel in 1874 that became the basis of which famous movie? .....
- 3/ Which island does Japan's capital city belong to? .....
- 4/ Complete the well-known proverb: An apple doesn't...? .....
- 5/ How old was Queen Victoria when she became Queen of England? .....
- 6/ Which of Snow White's dwarfs has the longest name? .....
- 7/ Coven is the collective name for a group of what? .....
- 8/ Which two aviators famously said, 'I feel the need – the need for speed'? .....
- 9/ Which song begins with the lyrics, 'I know I stand in line until you think you have the time spend an evening with me'? .....
- 10/ How many gold medals did Mo Farah win at the 2016 Summer Olympics? .....

Name:

Address:

Send Completed Forms To:  
Mr D Henderson  
74 Windermere Road  
Stockton-on-Tees  
Cleveland TS18 4LY

All entries to be received by the next social. The winner will be drawn from entries received with the highest number of correct answers.

Answers to last quiz:

1/ Vietnam War 2/ Coca Cola 3/ The Wet Bandits 4/ Pickle (Gherkin) 5/ Love is All Around  
6/ Wassail 7/ Yule Log 8/ Six 9/ Four 10/ True